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A community-engaged infection prevention and control approach to Ebola

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Authors' note

Since this article went to press, evidence has emerged of a recent and substantial decline in new Ebola cases and fatalities in the affected countries. However, this and other Viral Hemorrhagic Fevers remain a reality and tend to occur in cycles. The process presented in this paper still has relevance for prevention and containment efforts, both now and in the future.

Summary

The real missing link in Ebola control efforts to date may lie in the failure to apply core principles of health promotion: the early, active and sustained engagement of affected communities, their trusted leaders, networks and lay knowledge, to help inform what local control teams do, and how they may better do it, in partnership with communities. The predominant focus on viral transmission has inadvertently stigmatized and created fear-driven responses among affected individuals, families and communities. While rigorous adherence to standard infection prevention and control (IPC) precautions and safety standards for Ebola is critical, we may be more successful if we validate and combine local community knowledge and experiences with that of IPC medical teams. In an environment of trust, community partners can help us learn of modest adjustments that would not compromise safety but could improve community understanding of, and responses to, disease control protocol, so that it better reflects their 'community protocol' (local customs, beliefs, knowledge and practices) and concerns.

Drawing on the experience of local experts in several African nations and of community-engaged health promotion leaders in the USA, Canada and WHO, we present an eight step model, from entering communities with cultural humility, through reciprocal learning and trust, multi-method communication, development of the joint protocol, to assessing progress and outcomes and building for sustainability. Using examples of changes that are culturally relevant yet maintain safety, we illustrate how often minor adjustments can help prevent and treat the most serious emerging infectious disease since HIV/AIDS.

Key words: community participation, Ebola, IPC, global health

INTRODUCTION

Although at least 20 outbreaks of Ebola virus disease (Ebola) have occurred since the virus was first recognized in humans in 1976, the 2014 outbreak was unprecedented in size and severity. By the end of December, over 20 000 persons had been infected and close to 8000 had died, with 99% of cases originating in the West African nations of Guinea, Liberia and Sierra Leone (WHO, 2014a). As of 3 December 2014, 622 health workers had been infected of whom 342, or 55.0% had died (National Institute for Communicable Diseases, 2014). Poverty, a weak health care system, lack of access to resources, recent civil conflicts and their aftermath and the prevalence of informal settlements, with overcrowded living conditions and weak hygiene infrastructure (Snyder *et al.*, 2014), are key among the broader social determinants of Ebola. Yet even the most vulnerable communities also possess important assets that, when valued and mobilized, can make a difference in the prevention and containment of this most serious emerging infectious disease since HIV/AIDS disease.

The missing link in Ebola control efforts to date may be the early, active and sustained engagement of communities, their formal and informal leaders, social and health networks and experiences and lay knowledge, to help inform the work of external disease control teams, *in partnership with the affected communities*. The predominant focus on surveillance and prevention of viral transmission, while understandable, has inadvertently stigmatized and created fear-driven responses among affected individuals, families and communities. These same communities, however, are the repositories of often unrecognized or unappreciated knowledge and experience that comprise sustainable assets towards disease prevention and control. While rigorous adherence to both standard infection prevention and control (IPC) precautions, and safety standards for Ebola and other viral haemorrhagic fevers (VHFs) containment is critical, we can be more successful in control efforts if we integrate local community knowledge with that of IPC medical teams. In an environment of

trust and engagement, the contribution of communities as partners promotes respect for and important new knowledge about cultural values, customs, practices, contexts and concerns. For example, community members have observed children waiting under trees to eat fruit dropped by fruit bats—potential transmitters of the Ebola virus.

Community partnerships can prevent rumours, fear and distrust that have sometimes resulted in the hiding of ill or dying family members. WHO guidelines on safe burial of Ebola victims (WHO, 2014b) exemplify the utility of this approach. Prepared in consultation with medical agencies, community members and faith-based organizations, the guidelines stress that while burials must be safe, they can still be dignified, taking cultural and religious beliefs into account and, in the process, building trust with communities.

Drawing on the insights of health care workers and community members from diverse African nations, we propose eight interconnected steps for engaging communities and their lay knowledge in a safe, but more inclusive evidence-driven response to disease prevention and control. Each step is grounded in ‘practice-based evidence’ (Green, 2008) and evidence-informed practice from health promotion and disease prevention, including substantial literature on community engagement (Eng *et al.*, 1990; Gibson *et al.*, 1998; Corburn, 2005; Mosavel *et al.*, 2005; Marais, 2007; Minkler and Wallerstein, 2008; Chirowodza *et al.*, 2009; Lavery *et al.*, 2010; CDC, 2011; Wallerstein *et al.*, 2015).

The eight-step approach is aligned with the new Community, Assets, Responsiveness and Evaluation (CARE) Model being developed for front-line infectious disease control practitioners (Marais *et al.*, 2014). The CARE Model offers guidance for the development, implementation and evaluation of community-engaged responsive and culturally congruent control efforts towards prevention, treatment, containment and self-care of Ebola and other VHFs. Yet health promotion theorists and practitioners, who understand the importance of working *with*, rather than *on* communities, must also be

part of the dialogue on participatory efforts to prevent and contain Ebola and other VHF.

EBOLA VIRUS DISEASE: A BRIEF OVERVIEW

Although the virus causing Ebola has been present in fruit bats and marsupials for at least 10 million years (Taylor *et al.*, 2014), the disease was first recognized in humans less than 40 years ago (WHO, 2014b). Caused by a filovirus in the same category as Marburg and other VHFs, Ebola outbreaks, until now, have been small, and none has been as deadly or geographically widespread as the current outbreak in West Africa. This outbreak was first notified by the WHO in March 2014 which declared it a Public Health Emergency of International Concern in August (WHO, 2014b). Although some areas, e.g. Senegal and Nigeria, appear to have successfully contained the disease, its persistence in Liberia, re-emergence in Mali (CDC, 2014; McNeil, 2014) and increasing intensity in Western and Northern Sierra Leone are cause for concern. The traditional course of Ebola is well documented (Preston, 1995, 2012; WHO, 2014b). Humans become infected with the virus through contact with meat or leftover fruit/food from infected fruit bats, primates and some antelopes. The virus does not spread through air, water, mosquitoes or other insects. Person-to-person transmission occurs through direct contact with broken skin or mucous membrane; blood and body fluids, including, but not limited to, urine, saliva, perspiration, faeces, mucus, vomitus, breast milk and semen. Further, the virus has been detected in the semen of men for up to seven weeks after recovery from Ebola. Accordingly, recovered men are advised to abstain from sex (including oral sex) or to use condoms for up to 3 months to help prevent transmission of Ebola (CDC, 2014 etc.). The virus additionally can be spread through contact with contaminated objects, clothing and bedding, and frequently also is transmitted through close contact with the bodies of people who have died of Ebola.

The incubation period (time interval from infection to onset of disease symptoms) is 2 to 21 days. Symptoms of Ebola include sudden onset of fever and fatigue, muscle pain, headache, sore throat with progression to diarrhoea, vomiting and organ failure and in some cases, both internal and external bleeding which are often fatal if untreated with supportive care-rehydration (oral and/or intravenous fluids), and treatment of specific symptoms. Although a range of potential treatments is being evaluated, there is currently no proven curative treatment or licensed vaccine available for Ebola. The appropriate ways to manage the incubation period also are contested, with some exposed health care workers, for example, honouring self-imposed

limitations on their movements and associations, and others choosing to ignore government imposed limitations, including those in some European and North American regions, where returning health care workers are subject to different rules depending on the country of departure or state or country they enter.

Ebola outbreak containment is achieved through measures that include IPC precautions, case management, contact tracing, health communication and community education, ideally guided by and implemented in partnership with the affected communities. Following a brief review of community engagement, we discuss eight steps that can make a difference in the critical, and too often ignored, community partnership dimension of containment efforts.

COMMUNITY ENGAGEMENT AS A FRAMEWORK FOR JOINT ACTION

Numerous scholars, practitioners and organizations including The Global Fund (The Global Fund, 2014), NIH (NIH, 2014), WHO (WHO, 1986), the CDC (CDC, 2011), the Pan American Health Organization (Wallerstein and Duran, 2006) and the Institute of Medicine (Gebbie *et al.*, 2003) have offered guidance on authentically engaging and partnering with communities (Labonte, 1993) in planning, implementing and evaluating relevant public health responses, including culturally effective methods of tracking and treating the disease and monitoring results (Calain, 2007a,b). To date, however, and with some important exceptions (Dramowski and Mehtar, 2014; Marais *et al.*, 2014; Reaves *et al.*, 2014; UNICEF and WHO, 2014; WHO, 2014b), the response to Ebola and other VHFs, while understandably focused on IPC safety protocols, has missed an opportunity to work closely with affected communities and their trusted leaders from the outset. The steps below, while not new to health promotion researchers and practitioners, are tailored to Ebola and other VHFs. Although presented in a linear format, the steps are interconnected and overlap will occur in practice, as will further adaptation to the culture and context of affected communities.

Step 1. Prepare to enter the affected community

Just as medical control teams would not enter households and communities affected by Ebola or other VHFs without the proper personal protective equipment, a sincere effort should be made by the health care team before entering each community to learn about local culture and governance structures and to identify respected leaders and other key decision makers who allocate resources and provide

links with other associations and networks. Such information can be gathered prior to entry from a variety of sources such as Internet data bases, relevant literature and community-based organizations operating in the region.

Survivors of Ebola and other VHF s may also be invaluable sources of information if they can be reached and are comfortable sharing their experiences. For example, at the recent first Ebola survivors conference in Sierra Leone, survivors revealed their stories, including both physical and psycho-social after-effects of the disease, and considered how they might contribute to containing the first Ebola epidemic the world has ever known (WHO, 2014c). The global organization Slum/Shack Dwellers International (SDI) (www.sdinet.org), which operates in 33 nations in Africa alone, is an important source of information about informal settlements or slums. In Sierra Leone, 97% of the urban population lived in such settlements by 2005 (UN, 2006/2007), whose abject living conditions are major contributors to the spread of Ebola (Snyder *et al.*, 2014). Through SDI, local residents, often in partnership with universities, collect detailed information on their communities using GPS, door-to-door surveys and other means. SDI members can provide vital information concerning local infrastructure (access to safe water, sanitation, etc.) whether suspected cases or rumours about Ebola are present, as well as their community's perceived level of readiness to engage with outside medical personnel (Corburn and Karanja, 2016).

Prior to entering the community, it is important to contact a trusted and well-recognized community leader who will serve as a 'cultural guide' (Roe *et al.*, 1995). But knowing how best to approach such a leader respectfully in accordance with local cultural practices also is critical. In some communities, this may include bringing food gifts, while in others, such gestures could be seen as offensive. It will also be important to ensure that the local leader or another trusted person be on hand who is fluent in the local language or dialect, and can assist with the contextual application of some words or phrases.

Finally, locally appropriate media should announce, in multiple languages if needed, plans to engage a community or communities. Such information can prevent communities being caught unawares by entry of health care workers in 'space suits', sometimes accompanied by armed military or police personnel.

Step 2. Enter the community with cultural humility—and with local respected leaders

As Tervalon and Garcia (Tervalon and Garcia, 1998) point out, while we can never be truly competent in another's culture, we can approach communities and their members with cultural humility—a commitment to

self-reflection about our own biases, to learning about other cultures and community expertise (knowledge, skills and experiences), and to forming respectful and trusting community partnerships. The need for cultural humility refers not simply to race/ethnicity or social class, but to our status as physicians or other health care professionals as well (Tervalon and Garcia, 1998). In the context of Ebola, this means both sharing the rationale for and context of the VHF/IPC medical protocol and indicating, at the onset, a recognition that the 'community protocol'—local customs, beliefs, knowledge and practices—may have important contributions to make, without compromising safety.

Critical to demonstrating cultural humility in the context of Ebola is having the Coordinator/Head, or representative, of the VHF/IPC medical team enter and approach each affected community *accompanied by one or more recognized and trusted local community leaders* as indicated above.

Step 3. Identify additional respected male and female community leaders

Although entering the community with a respected local leader is an important way of showing the respect necessary for acceptance and initial work together, to be effective, others need to be involved as well. Of particular importance is identifying imams, priests, traditional healers and community health workers (CHWs), popular teachers and other individuals of both genders who have the respect of community members. Identification of such individuals does not require a lengthy academic stakeholder identification process; rather, questions like the following may be asked:

- Who do people go to here for advice or help?
- When the community had a problem in the past, who came together to help solve it?
- Who gets things done?
- Who are some other respected community leaders? If no women are mentioned, ask which women have the trust and respect of the community and/or of other women.
- Whose voices are the most influential in decision making? (Eng and Blanchard, 1990; Hancock and Minkler, 2012).

Information gathered from this dynamic process, including the names of people identified multiple times, will inform the establishment of an integrated community-medical partnership team. This team in turn will lay the foundation for authentic community engagement, increased reciprocal awareness, bi-directional communication and knowledge dissemination and enhanced acceptance and implementation of the VHF/IPC approach. Of particular importance is also

finding ways, early on, to involve survivors of Ebola, who not infrequently are shunned by some in their communities and branded as ‘witches’ for surviving (WHO, 2014c). Survivors may be trained as peer health promoters, for example, helping to identify and promote community-responsive recommendations and actions, while sharing their unique understanding and survival of this disease. Such engagement in disease prevention, treatment and containment may also help in the psycho-social recovery of individuals and in their destigmatization within communities.

Step 4. Organize regular community meetings to promote reciprocal learning and establish trust and respect

Low resource communities around the world are accustomed to meetings called by outsiders, in which they are informed of a new health threat and the need to comply with directions. Such meetings often are poorly attended and sometimes promote fear or further feelings of disconnect between health authorities and local residents.

An alternative approach, grounded in cultural humility, involves having respected community leaders organize the meeting, in a popular community meeting place and on the community’s timetable. Rather than calling or running the meeting, a few medical team members are invited as guests. The goal of the meeting is to engage in reciprocal learning and disease control actions based on facts, not fear.

Community meetings also provide a good platform for assessing ‘community readiness’ to help design, implement and evaluate required infection prevention and disease containment activities. Such community readiness may be indicated by the support of community leadership, the willingness and capacity of local people to participate (time, skills, supplies, etc.) and on-site mentoring (Edwards *et al.*, 2000; Ethnic Centre, 2014). The dynamic process of developing community readiness has been described by Edwards *et al.* (Edwards *et al.*, 2000) as progressing from no awareness and denial—the reported stages of many West African communities regarding Ebola until recently—through vague awareness, pre-planning and other stages of involvement and commitment, eventually achieving full engagement.

With this improved understanding and community readiness, a discussion would follow to identify aspects of the VHF/IPC protocol that might then be adjusted to improve cultural congruence, without any risks to individual resident/health care worker or community safety. As discussed below, something as simple as making time for a brief prayer before a family member with EVD/VHF symptoms is taken away for admission to a hospital/

treatment centre can make a real difference to a family and a community and may improve overall acceptance and promotion of the safety protocol.

Beyond the respected leaders and others taking part in an initial discussion, medical team members should underscore that communities possess a wide range of assets (Hancock, 2001). Community members can map these assets (McKnight and Kretzmann, 1988, 2012) for strengthening prevention, treatment and self-care. Assets may include faith-based groups and spiritual leaders, traditional healers, schools, youth and elders, market traders, barbershops and hairdressers, food stores, taxi drivers, CHWs and survivors of EVD/VHFs and their families. It is vital also to identify, with the communities, the most appropriate modes and methods for two-way knowledge dissemination and activation, and community education.

Beyond identifying community resources that can be mobilized to help address a disease outbreak, the very process of community mapping sends an important message. As McKnight and Kretzmann (McKnight and Kretzmann, 1988, 2012) note, it helps move away from the ‘deficit mentality’ which sees communities as a bundle of pathologies, to help create instead an ‘inventory of capacities’; in the process, community members and outsiders alike may see these communities in a new, more positive light.

The discussion of community assets will undoubtedly also include gaps such as shortages of resources and services, and other risks that need to be part of a community-informed response. In many communities in West Africa, markets, businesses, schools and colleges have been closed for some time. Thus, while the cost of food is escalating, income is decreasing, giving rise to other poverty and stress-related diseases that may be overlooked by Ebola-focused experts. Another concern is unrecognized ‘post-Ebola syndrome’ amongst survivors of the disease. This is marked by long-term disability, including frequent vision problems, making resumption of their former lives difficult, especially if manual work is involved, such as for farmers, labourers and housewives (WHO, 2014c). With guidance from the local leader/s and the community team, the medical team may be helped to better understand some of the broader individual and community risks. Where feasible, the engagement of children in asset and risk mapping may offer deep insight into the structural determinants of health, and sensitive and difficult-to-capture issues identified by children can create a platform for further exploration amongst adult community members (Kadir *et al.*, 2013). Finally, community members may help facilitate a process of turning problems into assets, as when nursing and medical students in Sierra Leone whose schools were closed went on bicycles to find suspected new Ebola cases (Redd, 2014).

Step 5. Develop a safe, collaborative community-medical Ebola/VHF control protocol

The above steps will pave the way for a community-engaged response to Ebola and other VHFs. Based on shared knowledge, the VHF/IPC protocol now would be adjusted to reflect community-responsive and culturally congruent control, without compromising standard IPC precautions and safety. Regular updates to family members on the location and health condition of their loved ones is a simple but important step identified by community members but other, more complex issues, also must be considered as part of an adjusted, culturally responsive VHF/IPC medical protocol.

From our conversations with community members and leaders in Sierra Leone, Liberia, Nigeria, Kenya and South Africa, as well as consultants with WHO and other organizations such as Infection Control Africa Network (ICAN), we offer several possible protocol adjustments in relation to one of the most difficult and important cultural rituals: burial. Because the body of a person who has died of Ebola is at its most contagious state, attention to safety protocols is paramount. Yet even here, safe options for burial rituals should be decided with the local community on a case-by-case basis. For example, the new WHO (WHO, 2014b) protocol suggests inviting the bereaved to be involved in digging graves (at least 2 m deep) for relatives, and providing options of a safe alternative to the ritual touching and washing of the dead. For instance, family members may be offered the opportunity to participate in the lowering of the coffin/body bag whilst wearing protective gloves (Dramowski and Mehtar, 2014). The agreement on alternative safe options for family involvement in burial rituals may reduce the practice of hiding bodies from burial teams, a risk factor that contributes to the spread of Ebola.

In some settings where many low-income residents own their own coffins, it may be that having the double-wrapped body placed in the person's coffin, followed by a brief prayer/blessing and/or traditional song and dance without physical contact before the body is taken away, would be safe and culturally appropriate. Yet because some urban communities still bury their dead in rural/ancestral lands, bodies may have to be transported long distances—a fact which could make such a practice unfeasible. In such instances, however, other, albeit more modest, adjustments may still be made, such as returning the ashes for traditional burial.

During this delicate process of discussing possible adjustments to the VHF/IPC medical protocol, every effort must be made to address tensions as they arise, and to carefully deal with conflicting opinions, as they can quickly threaten the trust building that has already taken place

(Butterfoss, 2013). As disagreements emerge they should immediately be addressed at joint community-medical partnership team meetings to continue building trust and respect, increase knowledge and address any new myths or rumours that have surfaced. Reciprocal learning, critical reflection and trust will again be a key part of this broader community meeting.

Step 6. Facilitate continued, multi-method communication

Interpersonal communication is often the most important means of information sharing at the community level and can be invaluable in 'getting the word out' about safe practices and new medical protocol adjustments. Yet word-of-mouth communication also has the potential to spread rumours and misinformation, which must be corrected quickly with accurate information from trusted sources. The fact that the new protocol will likely undergo further adjustments as new facts are uncovered also underscores the need for a system for regular, factual and timely knowledge transfer between the community and VHF/IPC medical team/s. Regular joint meetings and progress reviews are critical (Prata *et al.*, 2012).

In addition to regular meetings and interpersonal communication campaigns led by trusted sources, contextually appropriate strategies to counter rumours and provide new information may include radio, posters, leaflets, music/video, social media, street theatre and cell phone texting using sms and other available (free) apps, where feasible and appropriate. For example, the very popular 'Sierra Leone's Refugee All Stars' recently recorded a song about the Ebola crisis that will be widely played in West Africa (<http://sierraleonesrefugeeallstars.com>) and a short film conveying factual information about Ebola and dispelling rumours is widely available on the Internet (<http://weowntv.org>). Hip hop songs are being aired on local radio and social media platforms in Liberia to influence health behaviours and social change towards Ebola prevention (Del Rowe, 2014). Additionally, efforts are already underway for partnership with a major cell phone provider that has committed some funding for a system that would encourage community members to call in with questions or information that may be vital to prevention and containment efforts.

Step 7. Assess process, progress and outcomes

Tracking of progress, successes, failures and costs (Gibson *et al.*, 1998) is critical both for the current effort and for sustainability. To track the acceptability and effectiveness of a community-engaged response to Ebola and other

VHFs, continued attention to community and cultural context throughout the disease prevention, treatment and control continuum must be maintained. Three overarching questions are as follows:

- How responsive are the overall efforts in adhering to the collaborative community-medical Ebola/VHF control protocol?
- Is the protocol responsive and culturally congruent *without compromising safety*?
- Is the joint protocol perceived by the WHO and the national leadership as improving the community's responsiveness to and trust in the disease control efforts?

Effective tracking to acknowledge success and identify required corrective actions necessitates the establishment of baseline indicators for repeat assessments. Following agreement on the adjusted Ebola/VHF control protocol, the community-medical partnership team should jointly establish clear indicators for assessment of progress, outcomes, capacity building, participatory activities and processes (Minkler *et al.*, 2006; Marais, 2007; CDC, 2011; Butterfoss, 2013; Wallerstein *et al.*, 2015). Part of the regular community meetings in Step 4 should be used to conduct repeat participatory assessments in order to identify progress towards meeting the agreed upon indicators, the adequacy of or need for additional support and resources and change-producing actions.

As noted above, it is also important to seek information from Ebola/VHF survivors and their families and engage them in obtaining feedback from others, including children, who have survived the disease or lost family members. Such individuals may provide critically needed information on caring for survivors with post-Ebola syndrome that leads to long-term problems—physical, mental, social and economic (WHO, 2014c). Finally, their insider knowledge may be of great help in the design and testing of supportive programmes for Ebola survivors and their families. Nurses and CHWs can facilitate 'verbal autopsies' (Engmann *et al.*, 2012; WHO, 2012), focusing on which aspects of the community-medical Ebola/VHF control protocol were or were not adhered to in the cases where patients were lost. This process, successfully used in Northern Nigeria and elsewhere to study difficulties encountered in attempts to reduce maternal mortality, can yield a wealth of information, particularly when conducted soon after a death has occurred (Engmann *et al.*, 2012).

Based on information gleaned from the repeat assessments and other data sources, additional realistic and safe adjustments can be made to maintain and strengthen a community-engaged and culturally congruent protocol for the prevention and control of Ebola and other VHFs.

Step 8. Plan for sustainability

Planning for the departure of the VHF/IPC medical team members will be facilitated in concert with the community team, leaders and members so that the empowering process of prevention, treatment and self-care continues *by* the community and *for* the community in partnership *with* local health care workers and authorities well into the future. Of particular importance will be ensuring the continued training and support of CHWs, and clarification of their potentially changing roles in the process. Although Sierra Leone has a detailed government policy in this regard (Ministry of Health and Sanitation, 2012), other areas such as South Africa (Clarke *et al.*, 2008) have emphasized the need for more clarity going forward, which would only be intensified should an outbreak of Ebola or another VHF take place there. Laying careful groundwork for sustainability, including early building of individual and community capacity, is critical if a new or repeat crisis is to be averted or mitigated (Lavery *et al.*, 2010).

Before departure, the VHF/IPC team should ensure that the local public health care team has established a strong working relationship with the community team to sustain a proactive and dynamic community-medical partnership approach. This, too, will be essential for long-term sustainability and to reduce reliance on external support, which some African leaders see as perpetuating dependency over the long term (Lederer, 2014). It also will lay important groundwork for effective community engagement and safe and culturally appropriate responses to VHFs or other communicable diseases in the future.

DISCUSSION

In highlighting the general neglect of lay knowledge and community leaders and members as partners in recent efforts to contain the worst Ebola outbreak in history, we in no way mean to downplay the critical role of VHF/IPC medical teams, health care workers and support staff who risk their lives daily in efforts to prevent and contain this deadly disease. Worthy of note, too, are the health care workers, community members and others who contract Ebola yet return upon their recovery to continue to assist in prevention and control efforts.

Effectively addressing the Ebola outbreak requires vastly increasing the number of health care workers, on all levels, and improving the health care infrastructure, including provision of personal protective equipment and other worker safety measures, many new and upgraded treatment centres and better surveillance and reporting systems. Ongoing and updated training and support of

CHWs also will be critical. As noted above, Sierra Leone had developed a detailed policy on CHWs prior to the Ebola outbreak (Ministry of Health and Sanitation, 2012), emphasizing their vital role as community liaisons and clarifying their multiple functions and roles in the context of a more decentralized health care system. Yet the Ebola outbreak has added far more complexity along multiple dimensions of their work and relationships with local communities. Earlier work in South Africa has suggested that ‘political expectations of CHW interventions threaten to overwhelm CHW activities’ (Clarke *et al.*, 2008)—a reality that could be particularly problematic in the context of a crisis like an Ebola outbreak. Yet as we and others (Dramowski and Mehtar, 2014; Marais *et al.*, 2014; Reaves *et al.*, 2014; UNICEF and WHO, 2014; WHO, 2014b) have argued, approaches which rely solely on a medical model of prevention and treatment and fail to early and adequately engage communities as vital partners in this effort can miss valuable opportunities to improve the cultural and social acceptability of VHF/IPC protocols, while still maintaining safety.

Many examples of community engagement in public health in Africa (Eng *et al.*, 1990; Mosavel *et al.*, 2005; Chirowodza *et al.*, 2009; Prata *et al.*, 2012; Kadir *et al.*, 2013; Reaves *et al.*, 2014); and elsewhere (Gibson *et al.*, 1998; Corburn, 2005; Minkler *et al.* 2006; Marais, 2007; Wallerstein *et al.*, 2015) have informed our efforts to develop a contextually appropriate partnership approach for addressing Ebola. Prata and colleagues’ (Prata *et al.*, 2012) successful efforts to reduce extremely high rates of maternal mortality in Northern Nigeria illustrate that even when working under deeply hierarchical political and social conditions and in extremely impoverished communities, a modest level of community engagement can make a substantial difference in both health outcomes and capacity building. Chirowodza *et al.*’s (Chirowodza *et al.*, 2009) engagement of local residents in community mapping to better assess and inform HIV/AIDS treatment availability in South Africa also is instructive, in part in pointing out the limitations of ‘outside expert’ knowledge and understanding of true community identity and place, as well as geographical and other barriers to access. In a now classic study in Togo and Indonesia comparing intervention and control villages, Eng and her colleagues (Eng *et al.*, 1990) illustrate how community involvement in a water project had both short-term effects and longer-term consequences for significantly enhanced participation in an immunization campaign. Calain’s (Calain, 2007a) pilot studies in four low resource countries underline the need to build capacity and ‘empowerment of front-line health workers and communities for an effective surveillance system’ (p. 13). He further

argues that such an emphasis on local empowerment is likely to be more effective than many more expensive interventions. Finally, in Firestone, Liberia, a community-engaged response to the Ebola outbreak led to substantial victories, with community members identifying suspected Ebola cases, agreeing to voluntary quarantine in special facilities, and greatly diminishing the stigmatization of survivors of the disease. As Reaves *et al.* (Reaves *et al.*, 2014) have noted in reflecting on this experience, ‘The education, social mobilization, and reintegration programs, as well as the visibility of supervisors and leaders in the community, likely contributed to these successes’.

The interconnected eight-step approach we advocate is clearly in need of rigorous field testing and subsequent refinement and adaptation to particular contexts and circumstances. Full application of the model further may be resisted by health authorities and others concerned about the time-intensive nature of the process, particularly in situations like the current and unprecedented Ebola outbreak in West Africa. Yet as we have argued, when ill family members are being hidden, and highly contagious bodies buried unsafely due to fear and misunderstanding, adherence to a strictly medical IPC and safety protocol that does not include community trust building and partnership may be doomed to failure. The process we describe will add some front end time, yet even in situations of extreme urgency, the payoff is likely to be substantial. The model we offer, if successful, may leave behind enhanced community capacity and trust, and an approach to community-medical partnership that may be adaptable and scalable in many parts of the world to address subsequent outbreaks of VHFs, or other contagious diseases.

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REFERENCES

- Butterfoss F. D. (2013) *Ignite!: Getting Your Community Coalition "Fired Up" for Change*. Author House, Bloomington, Indiana.
- Calain P. (2007a) From the field side of the binoculars: a different view on global public health surveillance. *Health Policy & Planning*, **22**, 13–20.
- Calain P. (2007b) Exploring the international arena of global public health surveillance. *Health Policy & Planning*, **22**, 2–12.
- CDC. (2011) Clinical and Translational Science Awards Consortium. Community engagement key function committee task force on the principles of community engagement. *Principles of Community Engagement*, 2nd edition. NIH publication # 11-7782. <http://www.atsdr.cdc.gov/communityengagement/> (1 December 2014, date last accessed).
- CDC. (2014) Ebola (Ebola Virus Disease). <http://www.cdc.gov/vhf/ebola/outbreaks/2014-west-africa/index.html> (15 December 2014, date last accessed).
- CDC Ebola (Ebola Virus Disease). <http://www.cdc.gov/vhf/ebola/outbreaks/2014-west-africa/case-counts.html> (24 November 2014, date last accessed).
- Chirwodza A., van Rooyen H., Joseph P., Sikotoyi S., Richter L., Coat T. (2009) Using participatory methods and geographic information system (GIS) to prepare for an HIV community-based trial in Vulindlela, South Africa. *Journal of Community Psychology*, **37**, 41–57.
- Clarke M., Dick J., Lewin S. (2008) Community health workers in South Africa: where in this maze do we find ourselves?: primary health care: SAMJ forum. *South African Medical Journal*, **98**, 680–681.
- Corburn J. (2005) *Street Science. Community Knowledge and Environmental Health Justice*. MIT Press, Cambridge, MA.
- Corburn J., Karanja I. (2016) Informal settlements and a relational view of health in Nairobi, Kenya: sanitation, gender and dignity. *Health Promotion International*, **31**, 258–269.
- Del Rowe S. (2014) Songs teach Ebola prevention. *New York University Washington Square News*. October 27. www.nyunews.com/2014/10/27/hiphop (1 December 2014, date last accessed).
- Dramowski A., Mehtar S. (2014) *Ebola: Prevention Control*. Infection Control Africa Network (ICAN), Capetown, South Africa. <http://bettercare.co.za/books/infection-prevention-and-control> (1 December 2014, date last accessed).
- Edwards R., Jumper-Thurman P., Plested B., Oetting E., Swanson L. (2000) Community readiness: research to practice. *Journal of Community Psychology*, **28**, 291–307.
- Eng E., Blanchard L. (1990–91) Action-oriented community diagnosis: a health education tool. *International Journal of Community Health Education*, **11**, 93–110.
- Eng E., Briscoe J., Cunningham A. (1990) Participation effect from water projects on EPI. *Social Science & Medicine*, **30**, 1349–1358.
- Engmann D., Garces A., Jehan I., Ditekemena J., Phiri M., Thorsten V., et al. (2012) Birth attendants as perinatal verbal autopsy respondents in low- and middle-income countries: a viable alternative? *Bulletin of the World Health Organization*, **90**, 200–208.
- Ethnic Center (2014) *Community Readiness for Community Change*, 2nd edition. Tri-Ethnic Center for Prevention Research, Colorado State University, USA.
- Gebbie K., Rosenstock L., Hernandez L. M. (2003) *Who Will Keep the Public Healthy? Educating Health Professionals for the 21st Century*. Institute of Medicine/National Academies Press, Washington, DC.
- Gibson N., Boillot F., Jalloh F. (1998) TB in the Sierra Leone war zone: the patients' costs. *The International Journal of Tuberculosis and Lung Disease*, **2**, 726–731.
- Green L. W. (2008) Making research relevant: if it is an evidence-based practice, where's the practice-based evidence? *Family Practice*, **25**(Suppl 1), i20–i24.
- Hancock T. (2001) People, partnerships and human progress: building community capital. *Health Promotion International*, **16**, 275–280.
- Hancock T., Minkler M. (2012) Community health assessment or healthy community assessment: whose community? whose health? whose assessment? In Minkler M. (ed) *Community Organizing and Community Building for Health and Welfare*, 3rd edition. Rutgers University Press, New Brunswick, NJ, 153–170.
- Kadir A., Marais F., Desmond N. (2013) Community perceptions of the social determinants of child health in Western Cape, South Africa: neglect as a major indicator of child health and wellness. *Paediatrics and International Child Health*, **33**, 310–321.
- Labonte R. (1993) Community development and partnerships. *Canadian Journal of Public Health*, **84**, 237–240.
- Lavery J. V., Tinadana P. O., Scott T. W., Harrington L. C., Ramsey J. M., Ytuarte-Núñez C., James A. A. (2010) Towards a framework for community engagement in global health research. *Trends in Parasitology*, **26**, 279–283.
- Lederer E. M. Ebola countries to get \$450 million in financing. November 5, 2014. <http://www.wfmj.com/story/27298794/ebola-countries-to-get-450-million-in-financing> (20 November 2014, date last accessed).
- Marais F. (2007) Participatory public health research: the process of community engagement in research partnerships. *Pimatisiwin: A Journal of Indigenous and Aboriginal Community Health*, **5**, 77–106.
- Marais F., Minkler M., Gibson N., Mehtar S. (2014) *Community Assets, Responsiveness and Evaluation (CARE) Model: Community-engaged IPC for containment of Ebola and Other Viral Haemorrhagic Fevers*. Paper presented at the Annual Meeting of the Infection Control Africa Network (ICAN) in Harare, Zimbabwe, Nov. 5, 2014.
- McKnight J., Kretzmann J. (1988/2012) *Mapping Community Capacity*. Center for Urban Affairs and Policy Research, Northwestern University. Reprinted in Minkler, M. (2012) *Community Organizing and Community Building for Health and Welfare*, 3rd edition. Rutgers University Press, New Brunswick, NJ, pp. 171–186.

- McNeil D. G. (2014) Second Ebola outbreak in Mali eclipses early success. *The New York Times*. November 12. <http://www.nytimes.com/2014/11/13/health/mali-reports-a-second-larger-ebola-outbreak.html> (1 December 2014, date last accessed).
- Ministry of Health and Sanitation. Government of Sierra Leone. (2012) *Policy for Community Health Workers*. <http://www.kambia.org.uk/downloads/CHW-Policy.pdf> (1 December 2014, date last accessed).
- Minkler M., Wallerstein N. (eds) (2008) *Community-Based Participatory Research for Health: From Process to Outcomes*, 2nd edition. Jossey-Bass, San Francisco, CA.
- Minkler M., Vásquez Brechwich V., Warner J., Stuessey H., Facente S. (2006) Sowing the seeds of sustainable change: a community-university research and action partnership in Indiana and its aftermath. *Health Promotion International*, 21, 293–300.
- Mosavel M., Simon C., van Stade D., Buchbinder M. (2005) Community-based participatory research (CBPR) in South Africa: engaging multiple constituents to shape the research question. *Social Science & Medicine*, 61, 2577–2587.
- National Institute for Communicable Diseases. Division of the National Health Laboratory Service. *Ebola Virus Disease Outbreaks: Situation Update*, 12 December 2014, <http://www.nicd.ac.za/?page=alerts&id=5&rid=473> (15 December 2014, date last accessed).
- NIH (2014) *Community-based Participatory Research*. National Institutes of Health, USA http://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/ (1 December 2014, date last accessed).
- Prata N., Ejembi C., Fraser A., Shittu O., Minkler M. (2012) Community mobilization to reduce postpartum hemorrhage in home births in Northern Nigeria. *Social Science & Medicine*, 74, 1288–1296.
- Preston R. (1995, 2012) *The Hot Zone: The Terrifying True Story of the Origins of the Ebola Virus*. Anchor, Harpswell, ME.
- Reaves E. J., Mabande L. G., Thoroughman D. A., Arwady M. A., Montgomery J. M. (2014) Control of Ebola virus disease—Firestone District, Liberia, 2014. *MMWR*, 63, 959–965; <http://www.cdc.gov/mmwr/pdf/wk/mm6342.pdf> (1 December 2014, date last accessed).
- Redd J. (2014) Biological warfare: a CDC doctor on fighting Ebola. *Time*, 20 November 2014 online. <http://time.com/3596232/cdc-ebola-doctor-sierra-leone-interview> (26 November 2014, date last accessed). December 1–8, print.
- Roe K. M., Minkler M., Saunders F. F. (1995) Combining research, advocacy and education: the methods of the Grandparent Caregiver Study. *Health Education Quarterly*, 22, 458–775.
- Snyder R. E., Marlow M. A., Riley L. W. (2014) Ebola in urban slums: the elephant in the room. *The Lancet Global Health*, 2, e685.
- Taylor D.J., Ballinger M.J., Zhan J.J., Hanzly L.E., Bruenn J.A. (2014) Evidence that ebolaviruses and cuevaviruses have been diverging from marburgviruses since the Miocene. *PeerJ*, 2, e556. <http://dx.doi.org/10.7717/peerj.556> (12 November 2014, date last accessed).
- Tervalon M., Garcia J. (1998) Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. *Journal of Healthcare for the Poor and Underserved*, 9, 117–125.
- The Global Fund. (2014) *Community Systems Strengthening Framework*. The Global Fund, USA.
- United Nations Human Settlements Program. (2006/2007) The state of the world's cities. <http://mirror.unhabitat.org/pmss/listItemDetails.aspx?publicationID=2101>. (27 October 2014, date last accessed).
- UNICEF and WHO. (September 2014) Key messages for social mobilization and community engagement in intense transmission area Ebola Guidance Package. WHO reference number: WHO/EVD/Guidance/SocMob/14.1.
- Wallerstein N. B., Duran B. (2006) Using community-based participatory research to address health disparities. *Health Promotion Practice*, 7, 312–323.
- Wallerstein N., Sanchez V., Carter-Edwards L., Avila M., Minkler, M. (2015) Community engagement, community organizing and social action to improve health. In Glanz K., Rimer R., et al (eds), *Health Behavior and Health Education: Theory, Research and Practice*, 5th edition. John Wiley & Sons, New York.
- WHO. (1986) Ottawa charter for health promotion (1986). *First International Conference on Health Promotion*, Ottawa, 21 November, 1986. <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/index1.html> (24 November 2014, date last accessed).
- WHO. (2012) *Verbal Autopsy Standards: 2012 WHO Verbal Autopsy Instrument*. World Health Organization, Geneva.
- WHO. (2014a) Ebola virus disease. *Global Alert and Response*. <http://www.who.int/mediacentre/factsheets/fs103/en/> (10, January 2014, date last accessed).
- WHO. (2014b) *Field Situation: How to Conduct Safe and Dignified Burial of A Patient who has Died From Suspected or Confirmed Ebola Virus Disease*. World Health Organization, Geneva.
- WHO. (2014c) *Sierra Leone: Helping the Ebola Survivors Turn the Page*. http://who.int/features/2014/post-ebola-syndrome/en#.Vir_1tQS (14 December 2014, date last accessed).